

# Fetal alcohol spectrum disorders

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both cohorts, the rates for individuals with a FASD were higher than for typically developing persons, but lower compared to individuals with special needs. Pediatric problems, such as the demonstrated problems of incontinence, should be examined systematically. For individuals with a FASD, assessment of incontinence is worthwhile and if necessary, implementation of treatment is recommended. These are also important aspects for increasing self-confidence and quality of life for this target group.

### **FASD-related Stigma**

Women who drink during pregnancy, adoptive parents raising individuals with FASD, and FASD individuals may be subject to stigmatization. In **chapter 8** attention is given to stigma as well as to ethical and legal questions posed by FASD<sup>11</sup>. For FASD-related stigma, we described the four types that can be distinguished: self-stigma, public-stigma, stigma-by-association, and structural stigma. Results of our literature study showed public stigma to be the most common form of stigma. Prevention and stigma are sometimes contradictory. Well intended prevention programs targeting personal responsibility, for example, may unintentionally increase stigmatization. Currently, literature and theory provide us with insufficient guidance to reduce FASD-related stigma. In general, more knowledge is needed to identify and understand FASD-related stigma. Future research identifying underlying beliefs held by the general public about alcohol use during pregnancy, women who consume alcohol during pregnancy, and individuals with FASD is also warranted. Moreover, research should explore how health promoting programs can be developed without stigmatizing women who used or have used alcohol during pregnancy. One important guideline is to avoid threatening communications and other messages that associate the target behavior with disgust-related stimuli. From our literature review it is clear that research should also focus on alcohol problems in a broader context of lifestyle and environmental conditions.

## Valorization

### **Relevance**

The work described in this thesis has, besides a scientific relevance, also implications for health-care systems specifically and more generally for policy and society. FASD is a serious health problem with high inter-sectorial costs<sup>1</sup>. FASD as a consequence of alcohol consumption during pregnancy results in human suffering for those individuals, families, and caregivers involved. In addition to this burden - speaking in financial terms - not only health costs but also costs like loss of productivity are at stake. The studies described in this thesis offer ways to design future studies to systematically obtain the relevant information to close the gaps in the literature. FASD warrants simultaneous prevention on multiple levels and requires a multidisciplinary approach.

### Target groups

The research results described in our thesis are of interest for a wide range of stakeholders. Broader awareness is provided regarding the underestimation and underreporting of FASD and the need for further improvement of management and care among healthcare professionals. Also, program developers aimed at FASD prevention may benefit from the wide range of recommendations for systematic development of evidence-based strategies. Furthermore, this thesis ties in closely with the current developments on a national level including multiple stakeholders<sup>12</sup>. The Dutch Ministry of Health, Welfare and Sports is currently negotiating with various stakeholders from for example industry, governmental sectors, social organizations, and healthcare providers to launch a national prevention agreement on topics including prevention of harmful effects of alcohol. This thesis contributes to this important agreement by bringing awareness on the topic of FASD and the need for prevention. Furthermore, it provides clear recommendations on developing evidence-based programs including the importance of stigma. The relevance of this topic is also aimed at an entire society in terms of responsibility for healthy pregnancies and healthy babies.

### Activities and products

Outcomes from this thesis have also been disseminated through activities on a national, a European and a worldwide level. The authors of the articles presented herein were commissioned by the Dutch Ministry of Health, Welfare and Sports to write a FASD knowledge synthesis providing an overview of current knowledge and gaps in knowledge regarding FASD prevalence, prevention, diagnosis, management and treatment<sup>1</sup>. In this synthesis, recommendations for an action plan based on prioritization of FASD knowledge needs and questions are presented. Moreover, tailor-made training programs were developed and offered through the Orange Knowledge Program (Nuffic TMT program). This Orange Knowledge Tailor-Made Training supports organizations in developing countries by training a selected group of staff. Within our collaboration of Governor Kremers Centre – Maastricht University the Netherlands and the Foundation for Alcohol Related Research in South Africa we trained South African professionals in further developing FASD prevention programs in a systematic evidence-based way.

In Europe, systematic collaborations with other countries were realized, such as with the State Agency for the Prevention of Alcohol-Related Problems (PARPA) in Poland and in Germany with the Ministry of Health (Ministerium für Gesundheit) Saarland and the Saarland University hospital Homburg (UKS, Universitätsklinikum des Saarlandes).

European FASD networks have furthermore been developed and strengthened in close collaboration with the European FASD Alliance (EUFASD). Together with the EUFASD and Eurocare we are coordinating activities to develop, pilot and evaluate brief interventions to reduce the

risk of FASD and build new capacity for bringing various stakeholders together in the European regions (chafea.b.01(2018)5494555, COST Action).

Internationally, recent activities involved launching a Global FASD Alliance together with the EUFASD Alliance (February 2018). This global FASD Alliance was introduced by the EUFASD Alliance at the Câmara Municipal de Ribeirão Preto, Brazil.

Together with partners in Australia, Canada, South Africa, and the United States an international FASD prevention network has been established. Activities of this network resulted in joined symposia during international conferences (EUFASD conference London 2016, FASD conference Vancouver 2017, and EUFASD conference Berlin 2018).

### **Innovation**

Besides the wide range of various activities and products, this thesis also presents innovation potentials. These include FASD cross-disciplinary working groups, creating awareness and seeking consensus for policy and practice, identifying evidence-based strategies, building capacity to foster and disseminate interdisciplinary evidence-based approaches, and identifying methods and tools to facilitate multiscale biomedical data for FASD understanding and prevention.

### **Schedule & Implementation**

Our Governor Kremers Centre-Maastricht University FASD research activities will be further developed through European funding possibilities such as COST Action and a European Tender by the European Commission for consumers, health, agriculture and food executive agency (CHAFEA) (chafea.b.01(2018)5494555). Furthermore, the Nuffic TMT offers opportunities to upscale our international projects. The current international collaborations will be further expanded with our Australian partner Telethon Kids Institute (exchange program professionals) and our European partner in Poland (State Agency for Prevention of Alcohol-Related Problems, PARPA).

## **Conclusion**

The research described within this thesis concerns the FASD topics of prevalence, alcohol consumption and psychosocial determinants, etiology and pathogenesis, incontinence as an example for a common neglected pediatric problem, and stigma.

The relevance of FASD as an important health problem in need of prevention was highlighted. The costs to society and to the health system are significant. In prenatally alcohol exposed individuals, multiple organ systems can be affected resulting in multiple symptoms and neu-